MEETING MINUTES
STATE CONSUMER FAMILY ADVISORY COMMITTEE
JUNE 10, 2004

Present: Jere Annis, Derl Bruce, Pete Clary, Zack Commander, Sandy Dupuy, Ron Huber, Kathleen Herr, Ed Masters, Doug Michaels, Ellen Perry, Barbara Richards, Katie Sawyer, Betty Stanberry, Amelia Thorpe, Alex Vasquez, and Paula Wagner.
Absent: Carl Britton-Watkins, Ben Jones
DHHS Staff Present: Donnie Charleston, Yolanda Hunter, Cathy Kocian, Chris Phillips, and Ann Remington
Facilitator: Beth Melcher

I.   **Welcome**
   ♦ Ann Remington welcomed everyone.
   ♦ Carl Britton-Watkins and Ben Jones were absent due to illness.
   ♦ Due to traffic conditions, the agenda was switched to accommodate those arriving later. A power point presentation on the Mental Health Commission and on Division Advisory Councils was given followed by an exercise designed to allow members to become acquainted with one another.

II. **Commission and Council PowerPoint – Complete handout of presentation distributed to members.**
   ♦ This was an overview of the Mental Health Commission and the various Division Advisory Councils. All information presented can be found on the state web site www.dhhs.state.nc.us/mhddsas. Look in the upper left corner under announcements to find Commissions, Councils, Training and Publications.
   ♦ The 2004 member list of the Commission can be found at this web site. www.dhhs.state.nc.us/mhddsas/commission/commissionmembership4-27-04.pdf
   ♦ The committee would like to have someone from the Mental Health Commission, GACPD (Governor's Advocacy Council for People with Disabilities), Mental Health Planning Council and the Division's External Stakeholders Group to make informational presentations.
   ♦ It was mentioned that 2 to 3 SCFAC members could also meet with the Mental Health Commission to exchange information.
   ♦ SCFAC wants to be added to the Commission's mailing list for minutes and vice versa. Chris Phillips stated he would look into this for the committee.
   ♦ The GACPD is trying to become re-designated as a non-profit rather than being under the Department of Administration as there are inherent conflicts with an "external advocacy group" being administered by a state agency. Concerns were stated regarding the fact that substance abuse is not listed on the GACPD website as a medical condition that meets the criteria for advocacy services.
   ♦ The Mental Health Advisory Council for the Deaf and Hard of Hearing lists the Director as the appointee. Chris Phillips stated that that needs to read the "Secretary appoints members."
   ♦ The SCFAC will receive a map of the state offices assisting the Deaf and Hard of Hearing.
   ♦ The DD Council has 34 projects going on at one time.

III.   Concerns regarding presentations given by other committees.
- ♦ The committee wants to be up-front as per their motive for asking another group to make a presentation. It was expressed that the expected outcome for any request for presentation would be to assist the SCFAC educationally or in helping it to structure itself. It is imperative that the forum allow for open questions from the floor and also allow adequate time for answers and discussion.
- ♦ It is essential that the SCFAC be very specific in their request by informing presenters from other groups ahead of time of topics and questions in which they have an interest.
- ♦ There was discussion about how a committee becomes an effective committee. The group decided that it was important to come up with creative ways to think "outside of the box," and to encourage people to do likewise for solutions.
- ♦ There was brief discussion regarding the nature of an advisory committee and the influence, authority and power of the SCFAC. It was re-stated that the SCFAC is an advisory committee, but can require responses. Comments were made regarding Carmen Hooker-Odom's request to change the culture of the Division and keep her apprised of issues from a consumer/family perspective.
- ♦ The Division is supposed to receive input from the SCFAC when developing policy.
- ♦ The group decided it is not really interested in having presentations made by other committees if they are not doing anything different from the SCFAC.
- ♦ It was agreed by the SCFAC that it will be the responsibility of the SCFAC to let the Division know about all presentations requests, in order for the Division staff to arrange the expert presenters.

IV.   It is important to know your committee.
- ♦ The committee broke into four groups in order to share information with each other about their personal advocacy success stories.
- ♦ Common things that were shared among the groups during this exercise:

-Frustration
-Desperation
-Determination
-Persistence
-Advocacy
-Expecting things to get better
-Optimism
-Sharing information
-Strategies
-Consistency when focusing on goals/outcomes
-Compassion
-Advocacy as a process
-Courage
-Transforming personal experiences to benefit advocacy.

-Enthusiasm
-How people can make a difference
-Effectiveness
-Pioneers
-Wisdom
-Being Informed
-Using experience, strength, and hope in order to move advocacy into the bigger picture.
-Remembering small successes and using those memories and experiences for future endeavors.

- The SCFAC is the voice for people with disabilities who cannot speak for themselves. The group talked about the reason for their existence and their mission. The importance of staying focused on the agenda and the importance of soliciting collective experience versus an individual agenda was discussed.
- There was discussion about the imperative that, as a group, the SCFAC share experience that is focused around priorities. Access and service gaps were mentioned as examples of priorities. None of the members present were interested in showing up once a month to stray away from topics and agenda.

V. Holly Riddle, NC Council on Developmental Disabilities
- Explained that wrap-around services are now Medicaid billable.
- Holly told the group that the majority of advocacy is done by parents.
- Holly stated that the DD Council is also a funding source and would be willing to fund and collaborate with the SCFAC on trainings.

VI. Approval of Minutes
- A motion was made, seconded and passed that the minutes from the previous meeting be approved.
- In the future, the committee will receive the minutes no later than 10 days prior to next meeting. The committee agreed to give feedback and corrections prior to the next meeting so they can receive a corrected copy at the meeting for approval/comments. The committee decided that everyone will respond to the minutes even if they have no corrections/feedback to make.
- Upon approval of minutes, the minutes will be posted on the web site.

VII. The Development of By-laws
- Beth Melcher is working to create by-laws.
- The group has no objections to asking Mark Botts from the Institute of Government for his feedback on draft by-laws.
- The plan is to hopefully have the SCFAC review a draft of the by-laws at the next meeting.

VIII. State-CFAC Rules of Operation (Code of Conduct)
- There was discussion of the need to have a Code of Conduct as many controversial issues will be addressed.
- A motion was made to accept the list (below) and then the motion was withdrawn due to additional input regarding a more inclusive list.
- A sub-committee was formed to review the list of possibilities. The members of the sub-committee are Jere Annis, Zack Commander, Doug Michaels (Point Person) and Ellen Perry.
- The committee will return all suggestions to Doug Michaels by June 25, 2004.
- **Value and Purpose for Meeting**
  Members should attend each meeting unless absence is unavoidable.
  The group should follow the agenda.
  Discussion should focus on one topic at a time.

Meetings should begin and end on time.
Members should be concise in their input.
Members should be prepared for each meeting.
The group should keep discussion relevant to the issue being discussed.

- **Promote Team Feeling**
The group should encourage participation and creative ideas.
The group should solicit input from all members—a few should not be
allowed to dominate the meeting.
All ideas should be considered.

- **Demonstrate Respect for All Participants**
The ideas and viewpoints of all members should be valued.
Individual agendas should be put aside.
Side conversations should be avoided and one person should speak at a
time.
All members should listen "actively."
Thought and consideration should be given before judging.

- **Create Harmonious Atmosphere**
Profanity and temperamental outbursts should be avoided.
Members should be positive and constructive in interactions and feedback.
Hostile humor should be avoided.

- **Ensure Closure and Strive for Consensus**
Action items should be defined.
Assignment of responsibility for action items and the establishment of
timelines should occur.
Follow-up on items should occur.

- **Additional Suggestions made by the committee**:
No cross talk should be allowed.
Definition of terms may be necessary.
The function of a time-keeper was discussed and the need for that person
to define a stopping point was expressed.
One person should speak when recognized by the chairperson.
The code of behavior should be defined in hopes that this will assist future
members in making decisions as to whether or not they can abide
by the code.
The membership should collectively monitor itself.
Members should avoid dominating, derailing, and making unnecessary
comments.

IX.   The Election of Officers
- The group has decided to elect a Chair for a two-year term and a Vice Chair.
- It is the intention that the Vice Chair will move up to the Chairperson position after the Chairperson's term expires.
- The committee will appoint sub-committees and each sub-committee will have a designated point person as needed.
- The group identified characteristics of the desired leaders:
  - Attention to detail,

- Diplomacy,
- Accepting,
- Non-judgmental,
- Reserved, yet able to move things along,
- Established leadership roles,
- Foster Collaboration,
- Consistent Commitment,
- Time available,
- Ability to develop an agenda and run a meeting,
- Creativity,
- Not intimidated,
- Good speaker,
- Good organizer,
- Patient,
- Positive communicator,
- Dedicated to goals and ideals,
- Leader,
- Good Vision,
- Consensus builder,
- Mediator and
- Problem solver.

♦ The group decided against an interim chair and it was agreed that the best solution would be to appoint a nominating committee at its meeting in July comprised of 3-4 members not interested in running for office. Members may self-nominate and others may nominate for Chair and Vice Chair to the nominating committee who will submit officer nominations at the August meeting.

♦ It is important to seek officers with long-term leadership experience.

X. Priority Areas as Determined by SCFAC Committee

Consumer Services

Quality
Best Practice and Person-centeredness

♦ Identify non-residential and residential programs (all disability categories) in NC that are examples of "best practices" (with a view to use these as models for future programs, to help define appropriate licensing requirements for such programs and to help establish an accessible database that will help meet needs appropriately).

♦ Identify ways to support front-line staff to understand person-centered planning/thinking.

♦ Develop a logical, systematic and timely schedule and system for training consumers, families, LME staff and provider staff on evidence-based Best Practices. This would include person-centered thinking and writing in consumer-friendly language.

Monitoring Processes

- Promote more active monitoring of the quality of services with state sanctions for those out of compliance.
- Investigate the feasibility of using more extensive oversight, review, and evaluation techniques to ensure safe and appropriate interactions between professionals and the consumers and family members they serve.
- Develop a strategy to address quality and accountability issues with consumers served by directly enrolled providers.
- Pilot a consumer empowerment survey to replace the state consumer satisfaction survey.

Justice System Issues

- Help establish guidelines for policies and procedures that will help eliminate inappropriate interaction between the MH/DD/SA communities and the justice system (e.g. investigate best practices in other states regarding policies/procedures/programs that help with jail diversion during emergency MH/DD/SA situations, investigate the feasibility of establishing MH courts throughout NC and create a protocol to investigate abuses at commitment hearings).
- Review accuracy and independence of competency evaluations at psychiatric hospitals

Gaps and needs:

Get Information

- Investigate concerns regarding loss of therapeutic services and loss of access to services.
- Identify gaps in services (Step 2 would be to cluster and prioritize addressing these gaps).

Service Definitions

- Promote Medicaid waivers in disability areas.
- Review and develop recommendations to streamline the qualification and authorization process for CAP.
- Promote development of eligibility criteria for MI children under 16.
- Identify the need for case management and CBS services.

Other

- Promote development of and access to crisis interventions and emergency placements staffed by MH/DD/SA professionals (not police).
- Promote development of services for youth in schools and communities.
- Promote transportation access for appointments, life needs and visits to family members in the hospital.
- Promote greater collaboration between LMEs and hospitals in MR/DD, MI and SA discharge planning.
- Advocate to state, county, local government on the need for more service dollars.
- Identify communities without Level III and/or Level IV Detox and recommend ways to develop services and/or to meet 30 mile/30 minute requirement.
- Review adequacy of rates for "Prevention" as a core service.

♦ Review community resources for non-target populations and make recommendations to support existing community groups to offer services.
♦ Develop a strategy for establishing regional services for particularly difficult populations (for example, the medically fragile mentally ill). In the interim, work to establish a service definition similar to partial hospitalization that allows those persons to be served in their own community with the skilled nursing or intermediate nursing care they need.

Effectiveness of services
♦ Promote the development of a community asset data base.
♦ Review why System of Care for children is not implemented in many areas.
♦ Review and make recommendations for improved dispensing of medications.
♦ Investigate and advise regarding NC's current laws and practices regarding involuntary commitment (e.g. mandatory handcuffing for all adults and children regardless of whether they are a danger to themselves or others). The investigation would involve identifying best practice models used in other states.

Support CFAC growth and development at the state and local level
♦ Promote statutory recognition of local CFACs to support their autonomy and continuity.
♦ Establish a logical, system-wide communication policy and strategy for communication flow between CFACs, the Division, LMEs and Division sections. This would include communications from the Advocacy and Customer Service Section.

Support individual (consumer) participation at the state and local level
♦ Promote development of information in Spanish, Braille, and American Sign Language.

XI.   Priorities Identified.
♦ The top three areas of concern include:
- Identification of non-residential and residential programs (all MH/DD/SA categories) in NC that are examples of "best practices" (with a view toward using these as models for future programs, helping define appropriate licensing requirements for such programs and helping establish an accessible database that will help meet needs more appropriately).
- Promote more active monitoring of the quality of services with state sanctions for those out of compliance.
- Develop a strategy to address quality and accountability issues with consumers served by directly enrolled providers.
♦ The second group of most important concerns identified were:
- Investigate concerns regarding loss of therapeutic services and loss of access to services.
- Promote transportation access for appointments, life needs and visits to family members in the hospital.

- Review community resources for non-target populations and make recommendations to support existing community groups to offer services.
♦ The group agreed that before they could take any action steps on these priorities, they needed to become more knowledgeable about the priority areas and about the general issues and concerns of the various disability groups. They agreed that at the next meeting members would educate each other about the disability issues and concerns. Subsequent meetings will begin to offer information sessions on the priorities identified above.

XII. Questions asked during this session

♦ What is the exact number of people with disabilities on the Mental Health Commission, and the disability representation on the Commission?
♦ What is the communication channel and flow of information of issues having been addressed by the Commission? What happens at the Division level with the information?
♦ Is it a conflict to sit on the Mental Health Commission and the SCFAC?
♦ Can you put the SCFAC on the Commission's minute mailing list and vice versa?
♦ Why are addiction disorders not listed on the GACPD web site as one of the eligible disabilities for advocacy services?
♦ When is the next Commission meeting and where is it going to be held?
♦ Does the Rules Committee have oversight on related public bodies, because the Medical Care Commission could be in conflict with the Commission for Health Services, Social Services Commission, and the Child Day Care Commission?

XIII. Next Meeting

♦ The next meeting is scheduled for July 8, 2004 at the NC Council on Developmental Disabilities www.nc-ddc.org. Directions are on next page.
♦ Until further notice, all meetings will be held in Raleigh.
♦ Locations discussed to hold possible meetings included the NC Psychological Association, NC Council on Developmental Disabilities, and the NC Council on Community Programs.
♦ A verbal consensus was taken regarding the committee meeting on the second Thursday of the month from 9:30 - 3:30 pm at an announced location. However, no official vote was taken to verify the set meeting date.
♦ In order to understand the language of the people being served by each disability group, presentations will be made by each group represented. It is important to know what the services are, and to understand the service definitions.

XIV. Agenda

♦ Presentations done by the Mental Health Commission and the External Stakeholders group.
♦ Disabilities education done by the SCFAC members.
♦ Committee Organizing Efforts:
  - Review draft by-laws.
  - Appoint a nominating sub-committee for election of officers.
  - Review suggestions made by Code of Conduct sub-committee (Doug Michaels, Point Person).

♦ Discussion of Newsletter Development.

Directions to the NC Council on Developmental Disabilities
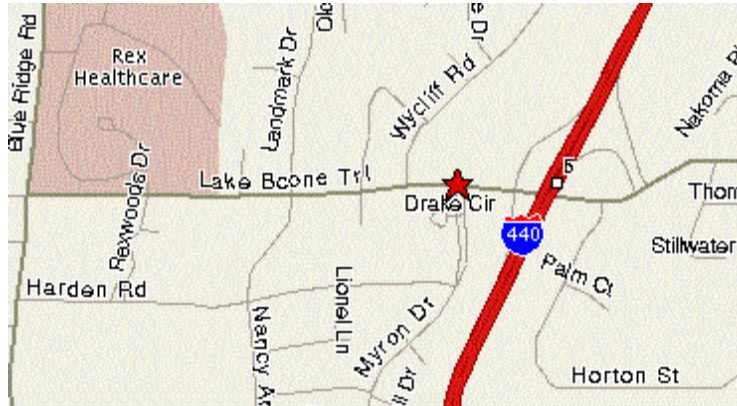
Take I-440 (Beltline) to Exit 5 - Lake Boone Trail. Turn towards Rex Hospital at the light. Make the first left (Corner of Lake Boone Trail and Myron Dr.). You will see Building 3801. NC DD Council is located on the second floor Suite 250.

NC Council on Developme ntal Disabilities

1-800-357-6916